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Hospitalized adults need their caregivers — they aren't visitors

By Jason Karlawish March 29, 2020



The Covid-19 pandemic has prompted hospitals across the country to limit or ban visitors. *Misha Friedman/Getty Images*

Social distancing, self-isolation, quarantine: These are among the essential public health interventions for the Covid-19 pandemic. As we use these strategies, we must also minimize their harms to the people they're intended to protect. One such person is my uncle.

If he's infected with Covid-19 and requires hospitalization, he's in big trouble. Smothering pneumonia can be deadly, but so can be care in the hospital. One problem I can see right away is that his hospital will deny him a critical intervention: me.

My uncle is 83. He lives alone, and he has Alzheimer's disease. Between us is a two-hour drive along the Northeast Corridor's busy highways.

We speak by phone two or three times a week, and a care manager visits him regularly. In the last few weeks, as I became increasingly concerned about Covid-19, we began talking daily. The care manager stops in to review his supplies of food and household goods.

All was OK. I was concerned, but I was also confident. We had a plan. But then I received an email from his regional hospital: “New visitor restrictions.”

In response to the Covid-19 pandemic, the hospital informed me that, “We ask that family and friends refrain from visiting, except in certain circumstances, including: hospice/end of life care, pediatric care, neonatal intensive care unit [for both, parents only], ambulatory care/same day surgery, maternity/labor and delivery.”

My anxiety escalated.

My uncle’s Alzheimer’s disease is at the mild cognitive impairment stage. He seems OK, but he isn’t. He’s inefficient in completing daily tasks, struggles to solve new problems, and, when time-pressured, makes mistakes. We’ve developed a system to watch over him. A key part of that is my being present when he sees physicians, especially if he’s sick.

I have a vivid memory of how important it is for someone to be present with him.

The most common medical complication you’ve never heard of

One year ago, my uncle had a heart attack and was admitted to the hospital that now won’t allow me to visit if he ends up there with Covid-19. Within minutes after stepping foot in his hospital room, I sensed something was wrong. He was *different*. He was repeating himself, confusing me with my brother, and asking what hotel this was. I realized he had developed delirium.

Delirium is a sudden onset of confusion and disordered thinking, a kind of acute brain failure. Alertness waxes and wanes. Some people with it are lethargic. Others become fiercely agitated, tearing out catheters and intravenous lines. Regardless of the response (my uncle was edging toward agitated, but I was able

to calm and redirect him), delirium has a common feature: Those who know the person well insist that he or she is really, really different.

That's why a visitor policy that doesn't acknowledge the need for a family caregiver for persons with cognitive impairment is misguided. I was with my uncle in his hospital room day and night. I'm convinced that had I not been his "visitor," he'd either be dead or severely disabled, likely not living in his home but in a long-term care facility.

Why? A [recent report](#) from AARP's Global Council on Brain Health, "Preserving Your Brain Health During Illness or Surgery," offers some insight.

The report is a call to action to families and health care systems. It explains that delirium makes a patient sicker in the short term and the long term and so extends their stay in the hospital and, after discharge, generally need long-term care at a skilled nursing facility or other institution.

Delirium is to Alzheimer's disease as pain is to cancer. Individuals living with Alzheimer's, or with other diseases that cause mild cognitive impairment and dementia, are at heightened risk for developing delirium and experiencing complications from it.

Patients and their families are clearly affected by delirium. Society suffers as well. The AARP report calls the financial costs "staggering." A 2008 study calculated that the health care costs of delirium range from [\\$38 billion to \\$152 billion](#) a year.

The good news is that as many as half of all cases of delirium could be prevented. Prevention starts with people like me.

Focus on the caregivers

Patients with diminished cognitive abilities or trouble communicating need other people to be with them. A mother or father accompanying a hospitalized child is not simply a "visitor," they're parents. The child needs a parent to help make decisions and provide reassurance and calmness — and so to heal.

In the same vein, I wasn't visiting my uncle. I was his caregiver.

Family members — people who know the hospitalized person well — are often the first to detect delirium, as I did for my uncle. After I diagnosed it, I helped take care of him. By being present, I was able to talk with him, redirect him, and make sure he ate, drank, and walked about.

I was especially needed because the hospital had no program in place to care for persons with delirium, such as the [Hospital Elder Life Program](#) (HELP). The program's multifaceted interventions have been proven to reduce the risk of delirium and, if it does occur, to minimize the harms. The interventions include reorienting the patient, making sure he or she is eating and drinking, minimizing distracting noises, and enlisting volunteers to help the patient get up and out of bed.

Sharon Inouye, creator of the HELP program and now a professor at Harvard explains, "Allowing a single caregiver to be present at the bedside is essential for delirium prevention and optimal care."

What Covid-19 is teaching us

During this pandemic, a hospital policy that restricts visitors is well meaning. People who don't provide care are viral vectors. For someone like me, however, "visitor" is a misnomer.

Should my uncle be admitted to the hospital, either because of Covid-19 or something else, he'll need me not simply to drop off a newspaper and flowers. Individuals with Alzheimer's disease, Parkinson's disease, head injury, Down syndrome, and other conditions have cognitive impairment. They're at heightened risk of delirium. They need a caregiver. Hospitals' Covid-19 "visitor policies" ought to acknowledge this.

Some do.

At Brigham and Women's Hospital in Boston, permitted visitors include caregivers for patients with "disruptive behavior, altered mental status, or

developmental delay.” Only one caregiver is allowed and is required to remain in the room. Although I take issue with the language, I applaud the intention of the message and as well the restrictions and conditions.

What can caregivers do if they cannot be present with their relative?

Elaine Fettig, a caregiver I know, shared her story with me. When her husband was recently admitted to a Philadelphia area hospital for a urinary tract infection, she was told “no visitors.” But the hospital took steps to make her as present as possible. Her husband’s nurse called her to learn about the severity of his cognitive problems and their cause. With this information, they assigned someone to be with him all night, and this person also facilitated frequent calls between him and family.

She was fortunate to have her husband cared for in a hospital where the principles of delirium detection and prevention are well in place.

When this pandemic is over, we ought to compare the outcomes of care in hospitals that recognized the role of caregiver and had programs like HELP and those that did not. I’d bet we would find that when caregivers were present, resources and lives were saved. Even more valuable will be the dignity we preserved when faced with a pandemic that threatened humanity. With these insights, we’ll change “visitor rules” to recognize the need for a caregiver for persons with cognitive impairment.

When this is over, we’ll take better care of each other.

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